Perceptions and Experiences of Patients Receiving Oral Chemotherapy

Brett Simchowitz, BA, Lawrence Shiman, MPP, Justin Spencer, MPA, Daniela Brouillard, BA, Anne Gross, RN, PhD, Maureen Connor, RN, MPH, and Saul N. Weingart, MD, PhD

Although many patients prefer orally administered cancer therapy (including oral chemotherapy) because of its convenience, the shift from hospital to home-based administration creates concerns. This article explores the perceptions and experiences of oral chemotherapy users and their caregivers to assess vulnerabilities and improvement opportunities at each stage of the medication process: choosing oral chemotherapy, prescribing, dispensing, administering, and monitoring. The authors recruited 15 current and former oral chemotherapy users, as well as caregivers who administered the medications to children, to participate in one of two focus group sessions at a comprehensive cancer center. Participants largely were satisfied with oral cancer therapy but raised concerns regarding their lack of preparedness for side effects and their unfamiliarity with the possible techniques to mitigate drug toxicity. Participants also described difficulties obtaining medications through retail pharmacies. Parents of pediatric patients with cancer indicated concerns regarding their children’s emotional health and correct medication administration. Participants believed that the initial prescribing encounter should have included more education, and they also wanted more frequent follow-up by healthcare practitioners. As oral cancer therapy is used more widely, oncology healthcare providers will need to create robust mechanisms to support their safe use.

Orally administered cancer treatments, including cytotoxic oral chemotherapies, have emerged as powerful tools in clinical oncology, accounting for a quarter of the 400 anticancer medications currently under development (Weingart et al., 2008). Accelerating oral cancer therapy’s popularity is the promise of convenience (Aisner, 2007), insurance coverage, and the perception that oral therapies result in fewer toxicities (Liu, Franssen, Fitch, & Warner, 1997; Weingart et al., 2008).

Unfortunately, the use of oral cancer treatment appears to have expanded more quickly than the infrastructure needed to ensure safe care. A survey of 42 U.S. cancer centers found that many commonly employed safeguards for infusion chemotherapy, such as templated orders and clinician double-checks, are lacking for oral agents (Weingart et al., 2007). Many centers had no formal protocols for monitoring oral drug adherence.

Ensuring the safe administration of oral cancer therapy poses a new challenge for patients as well. They have to navigate the process of securing medications from retail and mail-order pharmacies that are sometimes unfamiliar with the medications and then administer the drugs reliably without supervision (Weingart et al., 2008). Adherence rates for oral cancer therapy range from less than 20% to 100%, depending on the drug and patient population (Levine et al., 1987; Love, Cameron, Connell, & Leventhal, 1991; Partridge, Avorn, Wang, & Winer, 2002; Viele, 2007).

At a Glance

- Patients in focus groups identified multiple safety and reliability concerns regarding the prescribing, dispensing, administering, and monitoring of oral chemotherapy.
- Patients were concerned about the identification and management of side effects from oral cancer therapy, particularly among pediatric patients.
- Participants desired more comprehensive education at the initial prescribing encounter and more frequent provider-initiated follow-up.

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Despite the promise and potential pitfalls of oral cancer treatment, little is known about patients’ experiences with such medications. To address this gap, the authors undertook a hypothesis-generating focus group study designed to better understand how patients and their caregivers manage oral chemotherapy. They hoped that patients could identify vulnerabilities and opportunities for improvement in the process of using oral chemotherapy: choosing, prescribing, dispensing, administering, and monitoring these drugs.

Methods

Participants

The institutional review board of the Dana-Farber/Harvard Cancer Center in Boston, MA, approved the study protocol. The researchers recruited current and former users of so-called “targeted” and cytotoxic oral chemotherapy, as well as caregivers of children receiving oral chemotherapy, to participate in one of two focus group sessions at the comprehensive cancer center. The researchers recruited potential participants by asking oncologists at the center to recommend suitable patients and caregivers. The hospital’s adult and pediatric patient family advisory councils also publicized the project and forwarded the investigators’ contact information to interested parties. The researchers mailed a letter to candidates describing the study and followed up with no more than two telephone calls. Participants received parking, dinner, and $100 compensation.

Conduct of the Sessions

The researchers conducted two two-hour focus group sessions in June 2008. They described the study and gave participants the opportunity to ask questions before providing written informed consent. Participants completed a brief written survey that elicited sociodemographic data and general information about their use of oral chemotherapy. Participants were assured of the confidentiality of their responses.

A member of the study team facilitated both focus group sessions while other study team members observed and took notes. Sessions were highly interactive, and the facilitator used formatted and spontaneous probes to explore participants’ perceptions of and experiences with oral chemotherapy, covering all stages of the medication use process. Sessions were audiorecorded and transcribed for analysis.

Data Analyses

Surveys were tabulated to summarize participant characteristics, and investigators analyzed facilitator notes and written transcripts from the sessions using standard qualitative methods (Miles & Huberman, 1994). Specifically, the researchers grouped quotations from the transcripts based on the study objectives to which they referred. Next, the investigators reviewed the transcripts and notes from study team observers, identifying major and minor themes within each study objective until no new themes emerged (themeric saturation was reached).

Results

Participant Characteristics

Fifteen people participated in the focus groups, eight in the first session and seven in the second. Participants included 12 adult patients and three parents of pediatric patients with cancer. Seventy-three percent of participants were female, 93% were Caucasian, and the average age was 56 years old. Most (73%) had commercial insurance; 13% were covered by Medicare and 7% by Medicare (see Table 1).

All but one participant was using oral chemotherapy or administering it to a child at the time of the study. Although most participants used therapies approved by the U.S. Food and Drug Administration, two were participating in research studies. The average length of time on oral chemotherapy was 22 months (range = 2–72 months). Oral chemotherapies used or administered by participants included sunitinib, capecitabine, mercaptopurine, temozolomide, lapatinib, and imatinib.

Choosing Oral Chemotherapy

Most focus group participants chose oral chemotherapy at the recommendation of a doctor, including those who were placed on oral regimens as part of a research protocol. In addition to the information provided by their clinicians, all participants reported

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<td>CHARACTERISTIC</td>
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<td>Age (years)</td>
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<td>X = 56 ± 13.8</td>
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<td>Months using oral chemotherapy (for self or child)</td>
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N = 15
seeking additional information about oral chemotherapy from the Internet—cancer blogs, bulletin boards, and cancer organization Web sites—as well as from libraries, hospital support groups, family and friends, and pharmacists. Participants differed, however, in their levels of knowledge and desire for information. As one explained: “I mean, [clinicians] do give you a LOT of information to study, and if you’re self-motivated, you get onto the ‘Net and do some additional studies.” One participant went so far as to arrange a meeting with the researcher who had developed her oral chemotherapy, whereas another preferred to leave the decisions to her doctor: “All I know is that . . . my medical oncologist prescribed it for me and because I have confidence and I’m not educated in the medical field, . . . I’m taking it.”

Participants reported being largely satisfied with oral chemotherapy. They praised it for its effectiveness, although one patient wondered whether he would have done equally well off treatment. Most agreed that they preferred oral to IV chemotherapy for its convenience, ease of use, and painless administration. They appreciated the ability to take the medicines at home or while traveling, avoiding multiple trips to the hospital while nauseated or fatigued. The mother of a pediatric patient described the ability to deliver chemotherapy at home as a patient safety benefit, preventing her child from potential exposure to hospital-acquired infections. “I love the freedom of it,” said one patient. Another described having control over her chemotherapy as empowering: “I will not put . . . my whole entire life into someone’s hands, cause I realize doctors and nurses are human beings, and I like the fact that I am responsible for taking that every day, and it makes me feel stronger.”

Although none of the participants reported major drawbacks to oral chemotherapy, a few expressed reservations about beginning treatment. One woman said that she was uncomfortable with the idea of “being on this indefinitely,” and the parent of a pediatric patient recalled feeling trepidation about assuming responsibility for the delivery of her child’s chemotherapy: “So, you’re terrified, because this is your child, and you have to now be their caregiver . . . . In addition to being their parent, you have to be their caregiver.”

Prescribing Oral Chemotherapy

The researchers asked participants to discuss the initial clinical encounter at which oral chemotherapy was prescribed. Many participants stated that their doctors did an adequate job explaining the nature of oral agents and the process for taking them. Others, however, believed that important information was not initially covered in sufficient detail. As one patient put it: “I don’t think that they, you know, prepared us for what kind of journey we were gonna go on.”

Participants wanted more information at the initial encounter about all potential side effects, their severity, and the extent to which they might experience them, as well as help differentiating between “normal” and “red flag” events. They also wanted insight into how oral chemotherapy might interact with other medications they were taking.

Given the recent development of many oral agents, however, participants recognized that such information was not always available: “I’d like a little more warning as to potential side effects, and yet I don’t know if the medical staff knows enough to be able to give me those warnings.” Patients who had been enrolled previously in a research study complained that less information was provided when oral chemotherapy was prescribed off protocol. Research studies, they explained, seemed more “professional”—perhaps because the doctors were motivated to prevent protocol violations—and those participants desired a similar level of support for nonprotocol prescriptions.

Participants reported that a doctor prescribed the oral chemotherapy and introduced the patients to its use, but a nurse practitioner took the time to provide detailed instructions. “The NPs are, in my experience, immensely important, and they’re the ones who usually . . . sit down and have a long conversation with me. My doctor doesn’t have the time to have a long conversation, short of describing how I should take my pills.”

Nonetheless, participants agreed that they retained very little from the initial prescribing encounter. Many emphasized the value of having a friend or family member attend appointments to help process information. One patient said, “You’ve got to absorb so much, and especially for the patient, I mean, all of a sudden you draw a blank . . . when you hear some of the news. So when you have that secondary person there, they can absorb something.” Some patients, unwilling to sift through depressing stories and statistics online, relied on friends or family members to conduct Internet research and synthesize information.

Dispensing Oral Chemotherapy

Focus group participants filled their oral chemotherapy prescriptions at the cancer center pharmacy if they received the drugs as part of a research study; those who were prescribed the drugs off protocol used a retail, specialty, or mail-order pharmacy. One patient ordered her chemotherapy from France: “Every month, I pray it’s gonna be here.” Occasionally, retail pharmacies did not stock oral chemotherapy or had an insufficient quantity to fill a patient’s prescription. “They would say, like, ‘We can only give you half of it today. We ran out.’ So, sometimes I would have to come back like two or three times a week to get the full medication. But . . . that’s not happening as much, thank God.”

Insurance problems were common at retail pharmacies. One participant enlisted the help of his wife, a nurse, to negotiate with the insurance company. Another received assistance from his pharmacist, and yet another asked her U.S. senator to intervene on her behalf because of cost and coverage limitations.

All participants described positive interactions with their pharmacists. Pharmacists, they explained, were “kind,” “gracious,” and “very helpful” but sometimes seemed to know little about oral chemotherapies. The parent of a pediatric patient complained that retail pharmacists are “very, very unfamiliar with pediatric chemotherapy.” She preferred filling her child’s prescription at the cancer center pharmacy when possible.

All but four participants received their oral chemotherapies in pill bottles. Of the four without pill bottles, one received the medication in a blister pack and three parents of pediatric patients administered liquid medications. The instructions on the bottle were described as clear and straightforward, but participants reported occasional discrepancies between the
pharmacy’s directions and the doctor’s. In such cases, participants relied on the doctor’s or nurse practitioner’s direction, because oral chemotherapies are so new that recommended administration methods could vary.

### Administering Oral Chemotherapy

Participants generally agreed with a patient who described oral chemotherapy as “painfully easy” to administer, and most felt comfortable taking the medications after only a few weeks. Furthermore, most participants understood the importance of adherence to recommended dosages and were careful to take the medications as recommended. The parent of a pediatric patient explained that initially she had difficulty persuading her child to take the medications, but that oral administration at home was still far preferable to repeated trips to the hospital for IV chemotherapy.

Administration schedules and routines varied depending on the drug and the diagnosis, as well as the patient’s priorities. To promote adherence and minimize side effects, participants described incremental experimentation to develop their own personal regimens. Some oral chemotherapies should be taken with food, others on an empty stomach. One participant explained that although he usually took his oral chemotherapy in the morning, he occasionally postponed taking the drugs to prevent the resulting bouts of nausea from adversely affecting his work.

Participants described a variety of memory aids designed to remind them when to take—and when to withhold—their oral chemotherapies. Some put the medications in the same visible location (such as the refrigerator or kitchen counter) each day; others posted calendars in their homes and offices to help keep track of the on/off cycle patterns. An older adult said that her daughter often reminded her at the appropriate time to take her medication. In general, participants indicated that they had little difficulty taking their doses reliably within an hour of the prescribed time. As one patient said, “I myself feel very responsible because . . . the alternative is very scary. And so, I think that I’m very careful about it.” In case of a missed dose, participants followed the instructions provided by their clinicians. One participant said she made up a missed dose on her first day off cycle; another was told to skip missed doses entirely.

A problem with administration that emerged in the focus group discussions related to the proper handling of and exposure to oral chemotherapies by nonpatients. Some participants were told that oral chemotherapy could pose a danger to nonpatients through skin contact, or even through residue on a countertop or placemat. The information came as a surprise to other participants. After hearing the information, one patient was worried that she had been jeopardizing the safety of her family members: “I mean, I put it on my table, I put it all over the place! And I have grandchildren that come in the house and they—do you know what I mean? And nobody’s ever told me that.”

Another participant, whose husband frequently opened her pill bottle for her and handed her the tablets, said that her clinicians failed to warn her that her husband should avoid handling chemotherapy without proper precautions. Similarly, the parent of a pediatric patient described administering her child’s chemotherapy ungloved while pregnant—a potential hazard, she later learned. Participants agreed that the information should be presented reliably during the initial prescribing encounter to safeguard patients and their loved ones.

### Monitoring Oral Chemotherapy and Follow-Up

Most participants reported seeing the doctor or nurse on a regular basis for monitoring and follow-up, although the interval varied from a few days between home visits to one appointment every three months. Visits typically were used for tests or procedures or results, and they served as opportunities for the doctor to elicit information about side effects and for the patient to ask questions. Between appointments, participants were comfortable calling or e-mailing their providers, whom they found to be accessible and quick to respond.

However, many participants expressed a desire for their doctors or nurse practitioners to check in with them between appointments, especially to help them manage side effects. As one explained,

> It depends on me to get in touch with them. I would much prefer somebody to call me every one or two weeks, a nurse practitioner, and say, “Tell me what’s going on.” Rather than me trying to determine, “Well, . . . am I just imagining this damned thing? Is it a side effect? I’m gonna call these people again?” Call me, and ask ME what the hell’s goin’ on, and then they can help.

A patient with experience as a clinical trial participant noted that provider-initiated follow-up for oral chemotherapy off protocol was less intensive than that provided as part of the research study. “I can read through all the side effects, but once I went on this—as compared to the trial—you’re on your own,” he observed. “You never hear from anyone.” He echoed a theme of the focus group sessions: that support for off-protocol prescribing of oral chemotherapy should mirror that provided in clinical trials.

Participants displayed a range of expectations about medication-related adverse effects. Some expected the symptoms they experienced. For others, the side effects or their severity came as a surprise. They described how side effects “sneak up on you differently” with oral as opposed to IV chemotherapy, creating the false impression that oral chemotherapy is relatively innocuous.

I mean, if you were sitting in there, four days with a hose into you, you KNOW you’re gonna get hammered. You take this little pill, and then, in a couple of days all you’ve got is giant mouth sores, and the diarrhea doesn’t stop.

There was general agreement that patients would benefit from more detailed information at the initial prescribing encounter about the type and severity of side effects to expect from oral chemotherapy.

Participants suffered a variety of adverse effects, including diarrhea, constipation, nausea, mouth sores, loss of taste, intolerance to spicy foods, and soreness and peeling of the hands and feet (a feeling likened to “walking on bristles”). They worried that the most severe side effects may be yet to come, because the long-term effects of oral chemotherapy are unknown. Nevertheless, participants were willing to accept toxicity as the price of drug efficacy. As one explained, “I sound like I’m complaining, but I’m not. These [side effects] I can absorb and
I can live with, because if they’re taking care of the cancer in me . . . they’re fine.” Another said, “I look at it this way . . . you just have to endure them.”

Although most participants were able to tolerate the side effects they experienced, one patient admitted to stopping her chemotherapy unilaterally during a particularly painful bout, provoking her physician’s consternation.

The notion that side effects have to be “endured” for oral chemotherapy to be effective was prevalent among focus group participants, and some remembered being surprised and somewhat frightened when their clinicians first proposed dose or cycle-schedule adjustments to alleviate painful side effects. “I had no inkling that . . . if you react so badly that then they start decreasing the medicine,” remarked one patient. Another said, “I’ve been surprised a couple of times when the doctor said, ‘I can dose reduce you,’ and I felt . . . you know, here I am suffering and trying to really handle this cancer, and all of a sudden they tell me, ‘Oh, you’ve gotta stop.’”

This perspective was more common among older patients, who often took substantial side effects in stride, happy to be alive. In contrast, young adults reported a more negative attitude toward side effects. Some perceived that drug-related toxicities cheated them out of living normal lives. Similarly, parents had a difficult time watching their small children struggle with the adverse effects of therapy.

**Improving the Safety of Oral Chemotherapy**

Several participants related stories of errors encountered during the oral chemotherapy process. One patient’s electronic orders were either missing or incorrect on two separate occasions. Another noticed that he was dispensed the wrong dose of his chemotherapy, the result of an error in the pharmacy. A third, the parent of a pediatric patient, explained that a dose miscalculation resulted in too much chemotherapy being administered to her child. In another incident, the instructions on a patient’s pill bottle contradicted those given by a clinical trial staff member. When contacted for clarification, the staff member apologized profusely and explained that the bottle’s instructions were, in fact, correct. The trial was new, and the clinician was still learning about the protocol. In addition to errors with oral chemotherapies, participants reported problems with the prescribing and administration of associated drugs, including fulvestrant, zoledronic acid, and antiemetics.

To improve the safety of oral chemotherapies, participants suggested better communication at the initial prescribing encounter or prior to hospital discharge, more frequent provider-initiated contact between scheduled appointments, and the creation of a “side-effects specialist” position to educate patients about potential reactions and interactions. As one participant explained, although patients (or their caregivers) have a responsibility to be informed, to share relevant information, and to take their medications on time, the brunt of the education and monitoring burden lies with clinicians.

I really think [clinicians] need to look the parent [of the pediatric patient] in the eye and say, you know, “Repeat this back to me. Do you understand?” They can’t assume that you’re going to read up and know. . . . Not everybody’s going to be proactive.

Echoing that sentiment, another participant said,

“I feel kind of lost when I leave here, and I’m not gonna see the doctor for three months. I think that somebody from the office should be calling me every couple of weeks . . . And that would make me feel a hell of a lot better and would answer some of my questions without, you know, feeling like a fool sometimes.

In addition, participants emphasized the need for providers to stay up to date with the literature on oral chemotherapies, including the hazards associated with drug interactions. Lastly, focus group members highlighted the potential patient safety benefits that could be derived from enabling all patients to obtain their oral chemotherapies from the cancer center’s pharmacy. One participant observed, “There’s a hundred different ways you can get these medications! And there probably shouldn’t be. . . . You probably should . . . walk over to that window and get it from the best experts in the business and take it home with you.”

**Discussion**

In this focus group study, the investigators set out to understand the perceptions and experiences of patients receiving oral chemotherapy and their caregivers. Although participants reported being largely satisfied with oral chemotherapy, they described a need for more comprehensive patient education at the initial prescribing encounter, particularly regarding side effects and the handling of chemotherapeutic medicines by nonpatients. They also suggested frequent, provider-initiated follow-up. Patients with previous experience as research participants argued for resources and support systems equivalent to those provided as part of clinical trials.

The findings corroborate studies showing that many patients prefer oral to IV cancer therapies and home-based to hospital administration (Borner et al., 2002; Borner, Scheithauer, Twelves, Maroun, & Wilke, 2001; Miles & Huberman, 1994; Payne, 1992; Vinciguerra et al., 1986). Focus group participants cited the convenience of home administration as a significant advantage over parenteral administration in infusion units. Some found the ability to self-administer medications empowering, and one caregiver hypothesized that, by reducing the frequency of hospital visits and her child’s contact with other sick patients, oral chemotherapy offered a patient safety benefit. Participants described oral chemotherapy as easy to administer and generally agreed that clinicians were accessible and responsive when concerns arose.

At the same time, however, the findings offer a nuanced view of the psychological and practical drawbacks of oral cancer treatments. Some participants reported struggling to accept the notion that they might be on oral therapy indefinitely, because IV chemotherapies typically are given for a limited duration. A few participants (particularly those caring for pediatric patients with cancer) felt “terrified” by the magnitude of their responsibility. Participants who received assistance with their medications from family members worried that they were putting their loved ones at risk. Many participants felt unprepared for the severity of side effects and unsure as to which symptoms...
warranted a call to the doctor. Although some oral therapies may, in fact, be more tolerable than their parenteral counterparts (Cassidy et al., 2002; Depierre et al., 2001; Douillard et al., 2002; Hoff et al., 2001), the fact that oral cancer treatment allows patients to go for longer periods of time between clinician visits means that participants sometimes felt “on their own.” Some were unaware that doses could be modified to mitigate toxicity. Others neglected to mention side effects to clinicians for fear that a dose reduction would compromise treatment efficacy. Participants described few problems with adherence, although this is a well-known risk (Levine et al., 1987; Love et al., 1991; Partridge et al., 2002; Viele, 2007). Participants may have felt embarrassed to discuss their own administration errors or reluctant to assign some responsibility to their caregivers for supporting and documenting adherence.

Practical challenges associated with oral chemotherapy were primarily obtaining the medications from retail pharmacies, many of which did not stock the drugs or whose staff members were unfamiliar with the medications. A few participants described struggling to secure coverage for the drugs from their insurance companies, whereas others reported that occasionally the drugs were out of stock at the pharmacy. Given the narrow therapeutic range of oncology drugs and the need to avoid interruptions in treatment (Birner, 2003), such obstacles threaten to compromise treatment efficacy. Centralized dispensing of oral cancer treatments may improve the safety and reliability of the process.

This study has several limitations. First, participants were identified largely by their oncologists and were likely more knowledgeable and motivated than the average patient. Interestingly, adherence was not identified by focus group participants as a major challenge. They reported having little difficulty remembering their pills and rarely missing doses. Potential explanations for this discrepancy include the unreliability of self-reports (Levine et al., 1987) and a lower risk of nonadherence by virtue of participants’ socioeconomic status and self-selection (Lebovits et al., 1990). The authors acknowledge a selection bias but believe that their approach elicited many of the concerns and experiences that are common among oral chemotherapy users. Second, a limited number of orally administered cancer therapies were represented in the focus groups. The perceptions and experiences of patients using other medications may differ to some extent from those of the focus group participants. Third, the participants were drawn from a single comprehensive cancer center. Establishing the generalizability of the findings requires replication. For example, young adults and parents of pediatric patients appear to have different perceptions and experiences regarding adherence and side effects, but more research is necessary to confirm the differences. The authors’ confidence in the results, however, is supported by the congruence of the findings with those identified by a previous expert panel review (Weingart et al., 2008).

In conclusion, oral cancer treatments offer some patients with cancer the convenience of home-based self-administration. However, users encountered a number of problems with safe and reliable prescribing, dispensing, administering, and monitoring. Research is needed to develop and study: (a) interventions that educate patients and their families about the side effects of treatment and how to manage them; (b) clinical trials that support adherence and safe medication use through a combination of self-help, office visits, telephone outreach, and electronic communication; (c) demonstration projects that ensure patients’ uninterrupted access to oral cancer therapies; and (d) programs that ensure adequate psychological support for patients and caregivers who use oral cancer therapies. As these medications come into more widespread use, the oncology community will need to create more robust medical systems and workflow protocols to support their safe use.

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References


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